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Device modding: A way to improve type 1 diabetes care?

“It’s more fun to be a pirate than join the Navy”

Steve Jobs

Type 1 diabetes has reached something of a watershed moment, it seems. The Type 1 Diabetes Exchange (T1DX) has recently published its *Annual State of Type 1 Diabetes* report (T1DX, 2014). The document is clearly authoritative as it includes data from almost 27 000 people with type 1 diabetes, covering more than 70 “high-end” clinics in the US. Overall, the results are disappointing and, unfortunately, also in line with observations in the UK National Diabetes Audit (HSCIC, 2014).

The average HbA_{1c} for the T1DX Registry participants was higher than the target value set by the American Diabetes Association in almost all age groups, and was generally above 64 mmol/mol (8%). This value was similar to that reported in the UK National Diabetes Audit, in which less than 30% of individuals with type 1 diabetes were below the recommended value of 58 mmol/mol (7.5%). In comparison, the German and Austrian DPV (*Diabetes Patienten Verlaufsdokumentation*; Prospective Diabetes Follow-up Registry) had better results, with HbA_{1c} averaging 58 mmol/mol (7.4%; Maahs et al, 2014). Furthermore, the most striking difference between the T1DX and DPV results were seen in young children, with US youngsters struggling to achieve good control. It was also noteworthy that HbA_{1c} levels in the DPV group were similar irrespective of whether the treatment was based on insulin pump therapy or multiple daily injections of insulin. In the US cohort, depressingly, diabetic ketoacidosis still affects 10% of children with T1D each year, and 20% of adults reported seizure or loss of consciousness due to hypoglycaemia.

Compared with the UK, many more children and adults with T1D in the US – almost 60% – use an insulin pump. In contrast, less than 10% of young people and 20% of adults use a continuous glucose monitoring (CGM) device, with even fewer using it ≥6 days each week. For insulin pump therapy, the latest hot topic is the potential for the pump to be hacked, potentially allowing a third party to tinker with insulin infusion rates. This story first raised its head a few years ago, when a speaker at a conference for hackers was able to hack into his insulin pump live on stage (Kaplan, 2011). Recently, the US Department of Homeland Security has started investigating around two dozen cases of suspected cybersecurity flaws in

medical devices and hospital equipment that officials fear could be exploited by hackers. The devices under investigation are unknown but are likely to include insulin pumps, although an actual incident involving hacker-homicide using a medical device has not yet been reported outside of television fiction.

In direct contrast to worries related to hacking and insulin pumps, parents of children with diabetes have been recently given the OK to “mod,” or alter, their offspring’s existing diabetes devices in an attempt to improve safety (Linebaugh, 2014). Frustrated families are starting to meddle with their devices to make them more useful – in this case, a CGM device that allows concerned parents to track their children’s glucose levels using NightScout, “a system cobbled together by a constellation of software engineers, many with diabetic children, who were frustrated by the limitations of current technology.” This open-source system hacks into an existing CGM device, uploads its data online and allows parents to check blood glucose levels remotely on a phone, tablet or smart watch.

The elephant in this technology room is how lax the regulatory authorities will be when it comes to turning a blind eye to “home-made” medical technologies. Clearly there are safety concerns, but given the UK’s track record in type 1 diabetes care and the recent data from the T1DX, it does seem that the status quo is not worth pursuing. ■

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